

**Testimony of Silas D. Buchanan, The Cave Institute,
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HIT Policy Committee, Meaningful Use Workgroup

“Using HIT to Eliminate Disparities: A Focus on Solutions”

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Thank you for the opportunity to share my thoughts with you today. I am honored to have been invited. My name is Silas Buchanan and I am the Director of E-Health Initiatives for The Cave Institute. The Cave Institute is a Bethesda; Maryland based 501c3 dedicated to the elimination of racial and ethnic health and healthcare disparities.

Our vision is: Optimal health for everyone.

Our mission is: To help demystify HIT and inform communities of color and underserved communities about the benefits of adopting and utilizing HIT.

Our strategy is:

- To work with HIT application developers to innovate and/or adapt their products to better represent the wants and needs of communities of color and underserved communities.
- To work through the trusted leadership of credible, organized and sustained faith and community-based organizations to engage and educate people in underserved communities to encourage and increase usage of HIT.

Many HIT tools, applications, information, devices and resources are complex, not culturally-specific and many times intimidating to our targeted patient/consumers. We believe that underserved patient/consumers are at an increased risk of suffering greater disparities in health and health care simply because they are not being meaningfully engaged in the current technological shift. We are also cognizant that this meaningful engagement must employ more than web-based interventions with a targeted market that may or may not currently be online; there must be an offline strategy as well.

As physicians, hospital systems and other providers are currently being federally incentivized and subsidized to adopt HIT solutions, patient/consumers, particularly underserved patient/consumers, are often left unaware of the potentially transformative impact that HIT adoption can have on their lives. We believe that as billions of dollars are being spent to push technology down to providers we should also find a way to elevate consumers, particularly underserved consumers, up towards technology. It is critical that every American understand the benefits of adopting and utilizing HIT to improve their health outcomes. It is absolutely imperative that the current disparities in

health and healthcare not be exacerbated by a lack of thoughtful exposure, active engagement and/or culturally appropriate education around these benefits.

My remarks today are focused on how HIT solutions can be developed and implemented in meaningful ways to engage, activate, empower and motivate patient/consumers in communities of color and underserved communities.

1. What do you see as the greatest risks posed by the implementation of HIT in relationship to potentially increasing disparities in health processes and outcomes?

I see three very connected risks associated with HIT implementation in relationship to potentially increasing disparities:

- An increased disparity in knowledge about how HIT can improve health outcomes.
- A risk of further eroding an already fragile trust paradigm between healthcare systems/ providers and underserved communities.
- We risk missing the opportunity to have underserved patient/consumers participate in the innovation and development of new HIT products, services and devices.

As we continue to promote and encourage HIT proliferation, I am very concerned that the pace of innovation and the rate of adoption, adaption and usage of HIT by more affluent communities will far outpace the corresponding rate of adoption, adaption and usage of HIT in underserved communities. It will be to our collective detriment if HIT applications, tools and devices continue to be disproportionately innovated for, adapted and marketed to and used by, more affluent communities. It will continue to widen an already burgeoning disparity in HIT knowledge that portends that we might never really be on a level playing field. In other words; a more affluent patient/consumer might now be using a 4.0 version of Palm PDA, she is quickly adept at using the 4.0 version because she has owned the 3 previous versions. Meanwhile, a patient/consumer in an underserved community may never have had any of the previous 3 versions and when handed a 4.0 version she could, understandably, be quite intimidated and possibly frustrated enough to cause her to abandon it. And the disparity would continue to grow.

Engendering trust in underserved communities is a factor that should be strongly considered as a critical component to any successful intervention. A lack of trust by the leadership of influential organizations in underserved communities can easily translate to the community itself and should be viewed as a significant risk. Not having enough physicians of color and not having enough culturally competent physicians of *any* color has been a well documented issue. Frankly, I am concerned that, if we are not aggressive in our approach to reach underserved communities, we will have a web-based repeat of this problem as most major health-based web sites feature very few people of color. What is most concerning is that even on web pages detailing chronic illnesses that disproportionately impact communities of color, there is very little acknowledgement of health disparities.

The Cave Institute advocates that all patient/consumers be engaged in the meaningful use of HIT in a sincere and meaningful way. By that we mean that patient/consumers must be engaged and solutions developed that provide utility within the context of their daily reality. To accomplish this we believe that you must have the input of the community at the innovation stage of HIT. We strongly advocate designing and building web-based applications, tools and trackers *for* our targeted patient/consumers with input *from* our targeted patient/consumers and then directly promoting usage *to* our targeted patient/consumer.

Example: “I am a PC and Windows 7 was **my** Idea”

2. **What are you, or others with whom you work, doing (or planning to do) to reduce the risk of exacerbating disparities as HIT is implemented across the country.**

The Cave Institute is engaged in a community HIT education initiative targeting underserved community members in Central New Jersey. We have partnered with Meridian Health, the largest healthcare provider in Central New Jersey, No More Clipboard (NMC), an EMR/PHR application developer and the New Jersey Partners in Health and Latino Partners in Health. The Partners in Health represent a culturally diverse and influential microcosm of national and regional faith-based, fraternal, community and social organizations and are ingrained into the fabric of the community. Meridian Health currently promotes and encourages the use of the NMC un-tethered PHR and patient interface to all of its patient/consumers as a convenient and efficient way to engage and interact with Meridian Health’s providers and services. Meridian Health would like to promote and increase the usage of the NMC PHR and interface by its underserved patient/consumers. To that end, we will work with our partners and create a culturally and linguistically appropriate and bi-lingual user Demo of the NMC PHR and patient interface. We will then leverage the trust and goodwill of the Partners and Latino Partners in Health to:

1. **Expose 25,000** underserved individuals to the Meridian/NMC PHR and patient interface.
2. **Empower 12,500** underserved individuals to log-in and utilize the Meridian/NMC PHR and patient interface at least once.
3. **Motivate 6,500** underserved individuals to actively utilize the Meridian/NMC PHR and patient interface on a frequent and/or ongoing basis

As stated, the Partners and Latino Partners in Health are a microcosm of large, culturally diverse, national organizations that represent millions of our targeted patient/consumers. We have the commitment from several of these national organizations to scale this type of effort nationally. We also have interest from several other application developers, FQHC’s and healthcare systems to participate.

We are currently designing and will soon launch the <http://ehealthandme.com> educational platform to support these and similar efforts. **Our mantra is: Adoption + Adaption = Institutionalization, Meaningful Use and Disparity Reduction.**

3. What research is being done, or needs to be done, in this area to inform the HIT Policy Committee in trying to establish guidelines that will move providers to implement methods of using HIT to reduce disparities?

We believe that our hypothesis, Adoption + Adaption = Institutionalization, Meaningful Use and Disparity Reduction, as it relates to our Meridian project, could be more closely examined:

Our assumption is that most providers will not implement any method of using HIT until that method has been embedded/institutionalized in an HIT application and adopted by their healthcare system. Once that application has been adapted to be more culturally engaging, one could examine the accompanying utilization data between mainstream users and our targeted patient/consumers to begin the identification of HIT guidelines/strategies effective in eliminating race based disparities. The potential data analysis on behavioral change and its mapping that this project could generate would be significant. Our hope is that research will support our hypothesis and compel more HIT application developers to innovate tools, trackers and software with the input and needs of our targeted consumers in mind.

Our association partners; National Medical Association, Hispanic Medical Association, NAACP and the Joint Center for Political and Economic Affairs, understand the importance and urgency of identifying the strategies needed for underserved communities to equitably utilize HIT. They are supportive of our efforts and interested in learning more about research opportunities that would positively impact our targeted patient/consumer.

4. With patient and family engagement in care at the forefront of our thinking about improving our Nation's health, what particular strategies would you recommend to us as potential meaningful use requirements in 2013 and 2015 for the vulnerable populations we have asked you to address?

Because a stated goal of the meaningful use requirement is to; "Provide patients and families with access to data, knowledge, and tools to make informed decisions and to manage their health", we would like to see the mission and the budget of the REC's expanded to:

- Encourage adoption of HIT by patient/consumers and families
- Assist patient/consumers and families to become meaningful users of HIT
- Increase the probability that patient/consumers and family adopters of HIT will become meaningful users of the technology

There has been great care taken and budget allocated to establish a nationwide network of regional extension centers (REC's). We understand that it is to help primary care physicians and providers benefit from government programs that promote the adoption and "meaningful use" of HIT. I believe that the same care should be taken and an appropriate budget established, as part of a patient and family engagement strategy, to ensure that patient/consumers and families are similarly engaged. A specific focus on underserved patient/consumers and families could reduce health disparities and possibly also improve the cultural competency of physicians/providers further reducing disparities.

These expanded REC's would fit nicely in our community centers, community colleges and especially in our nation's libraries. A March, 2010 posting on the Bill and Melinda Gates Foundation web site indicates that 77 million people used library computers for Internet access last year. A subset of approximately 28 million of these users accessed health information, including information about diseases and illnesses. Underserved people are also the most likely group to use libraries as their sole source for Internet access. Libraries commonly conduct basic computer literacy classes on a regular basis. In essence, libraries already have the infrastructure in place that supports patient and family engagement in meaningful use.

5. How can the meaningful use of HIT specifically reduce a health disparity?

We should all be compelled, but we all are certainly, morally obligated to use HIT in meaningful ways to reduce health and healthcare disparities. Let me share a story that juxtaposes our current reality with what is possible to reduce a disparity through the meaningful use of HIT:

REAL: Prisoner number 23234 is, unfortunately, incarcerated. Along the way he has contracted a communicable disease that requires multiple medications taken multiple times everyday. For the last 5 years, at 10am and 2pm, prisoner number 23234 stands in line and opens his mouth, and prison officials throw in a pill. Last week prisoner 23234 was released; we should all be concerned because the infectious disease rates in our prisons are significantly higher than in our communities. Meaning we are all potentially impacted when a prisoner re-enters society. Upon release, prisoner 23234 may or may not follow-up with the FQHC near the half-way house where he lives and the FQHC likely does not have an electronic copy (or paper copy for that matter) of his prison medical record. Neither the county nor city public health departments are in the loop even though the health of the public, particularly in underserved communities, is at significant risk. In any event, he is released and is no longer prisoner number 23234, now he is just Thomas and there is no one standing in front of him at 10am and 2pm everyday to throw in a pill. So he doesn't take his pills and really doesn't understand the implications of not taking them. Recently, Thomas met a girl, a lovely lady that he conveniently did not apprise of his health status. They engaged in a consensual relationship and as a result, she now shares his health status, effectively increasing the disparity.

POSSIBLE: St. Mark's Church has a Prison Ministry that is authorized by their State Department of Corrections to shepherd and guide former prisoners as they transition back to society. Prisoner number 23234 meets a St. Marks Prison Minister in pre-release and joins the pre-release program. During his pre-release counseling, prisoner 23234 shares his health status with the St. Marks Prison Minister and authorizes, per HIPAA, the Prison medical office to share his complete medical record with the Prison Minister. He also learns where the FQHC, library and other community resources are located near the half-way house where he will live. Upon release, prisoner 23234, now known as Thomas, is given a culturally appropriate, avatar assisted, Church branded, electronic PHR. He is also given a USB drive that is pre-loaded with part of his prison medical record as well as addresses, phone numbers and directions to the FQHC. St. Marks also has a Health Ministry with an engaged Health Minister that teaches Thomas more about his condition and the implications of not taking his medication. As a result of the FCC's National Broadband Plan, the church has high-speed access to a Faith-based health information disseminating platform that is also socially networked to other Churches and Health Ministers around the country. The National Broadband Plan's focus on Digital Inclusion has helped St. Marks secure web-enabled, health information disseminating kiosk in the Church and another at the local community center. Not only does St. Mark's web portal disseminate culturally appropriate health information it also collects survey data that can be aggregated and shared with the Pastor so that he can guide St. Mark's grant writer. The grant writer has now positioned the Church to qualify for more local grants than ever before to focus on disparity reducing activities. Because St Marks is networked with other Churches in the State that employ the same platform, they are now positioned to collect more data and they jointly qualify for State and Federal grants to directly address disparities in their congregations and communities. St. Marks and the other Churches now have a productive working relationship with the neighborhood FQHC's, their State and local Departments of Public Health, the local support groups, community centers and the local libraries.

The Health Minister now works closely with Thomas to train him on how to maintain his PHR. Thomas also learns how to manage his condition and how to better protect himself and others. St. Mark's Health Minister automatically sends Thomas an SMS message everyday at 10am and 2pm reminding him to take his pill. Not only does Thomas take his pill everyday at 10am and 2pm but he has joined a group of others with his same condition that send simple and sometimes not so simple support messages to each other's cell phones. Thomas now self-manages his condition and importantly, he apprises his dates of his health status, effectively decreasing the disparity.

The Cave Institute is currently co-developing <http://ourhealthministry.com> to make what is Possible become our Reality.